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Emory University and Sophie's Voice Foundation Launch International Research and Prevention Center for Spina Bifida

Center is a private nonprofit and educational collaboration to eliminate preventable birth defect globally

May 24, 2012, Atlanta – The Rollins School of Public Health at Emory University (RSPH), Sophie's Voice Foundation (SVF), and Emory University School of Medicine Department of Pediatrics announced today the establishment of The Center for Spina Bifida Research, Prevention and Policy (CSB). The primary goal of the Center will be the total, global prevention of folic-acid preventable spina bifida over the next 10 years. The Center will also create programs to help advance the quality of life for individuals living with spina bifida, including individuals transitioning from pediatric to adult care.

Spina bifida, a neural tube birth defect, is one of the most complex birth defects compatible with life. In the United States, the annual cost of care and treatment of persons with this birth defect is estimated at a staggering \$1.4 billion.

Dr. William F. Foege, author and senior fellow with The Bill and Melinda Gates Foundation and professor emeritus at RSPH said, "The Center for Spina Bifida Research, Prevention and Policy is working toward prevention of spina bifida across the globe. Based on the successful prevention efforts in North America, within a decade or so, we can totally prevent this birth defect and improve the lives of children and adults."

Internationally, prevention efforts for spina bifida have achieved only 20 percent of what is possible with proper daily consumption of folic acid. Worldwide, more than 325,000 babies are born annually with neural tube birth defects – and 75 percent of these birth defects could have been prevented with folic acid. In 25 years, the polio eradication program reduced the number of polio cases from 350,000 to 500. The Center will seek to improve the lives of millions of families, just as the smallpox and polio eradication programs have done.

The Center for Spina Bifida Research, Prevention and Policy will collaborate with the Centers for Disease Control and Prevention's National Center for Birth Defects and Developmental Disabilities, the Flour Fortification Initiative and other international public, private, nonprofit and academic sectors in seeking its goal of achieving total prevention of folic acid preventable spina bifida by 2022.

"The Center for Spina Bifida Research, Prevention and Policy will provide an infrastructure and the resources to develop and implement a comprehensive plan seeking to prevent almost all new cases of spina bifida by 2022 – 30 years after CDC published the U.S. Public Health Service recommendation that all women of reproductive age should consume 400 micrograms of folic acid to prevent spina bifida and

other neural tube defects,” said Dr. Godfrey P. Oakley, the Center’s director and a professor of epidemiology at RSPH. Oakley also said the Center will seek to help those with spina bifida achieve their full potential through research and policy to create successful models for spina bifida healthcare, including transitions from childhood to adult care.

In partnership with other international spina bifida organizations, the Center will expand current research on spina bifida. Initial research will include epidemiologic research on deaths of young adults with spina bifida, seeking to identify preventable causes, and research focused on the use of anticonvulsant drugs that have been found to increase the risk of neural tube defects. The Center will also be active in research seeking also to provide the scientific foundation for the elimination of vitamin B12 deficiency diseases.

CSB is based at the Rollins School of Public Health at Emory University and will have employees based in countries worldwide. The Center, a 10-year \$50 million initiative, has the goal of the total global prevention of folic-acid spina bifida by 2022.

About Rollins School of Public Health at Emory University

The Rollins School of Public Health (RSPH) is one of six independent professional schools at Emory University. Administratively, the school is part of the Robert W. Woodruff Health Sciences Center (WHSC), Emory’s academic health science and service center focused on missions of teaching, research, health care and public service. The school comprises six academic departments, 20 interdisciplinary centers and more than 160 full-time faculty members. The RSPH ranks sixth among the nation’s 49 accredited schools of public health in U.S. News & World Report’s 2012 edition of America’s Best Graduate Schools.

About Sophie’s Voice Foundation (SVF)

Sophie’s Voice Foundation, headquartered in Atlanta, was established in 2008 by actors Boris Kodjoe and Nicole Ari Parker in honor of their daughter who was born with spina bifida. The mission of SVF is to elevate the quality of life for children and adults diagnosed with spina bifida and to raise awareness of its prevention.

About Emory University School of Medicine Department of Pediatrics

The Department of Pediatrics in Emory University’s School of Medicine is committed to providing children the highest quality state-of-the-art clinical care and improving how they are cared for through innovative scientific research and training the next generation of leaders in pediatrics. The Department provides clinical care to children at the Emory-Children’s Center, Georgia’s largest multispecialty pediatrics practice, and through Emory’s alliances with Children’s Healthcare of Atlanta, Grady Health System and Emory University Hospital Midtown.